



Developmental Perspective on Management of Childhood Chronic Diseases in Pediatric Practices

Pediatri Uygulamalarında Çocukluk Çağı Kronik Hastalıklarının Yönetimine İlişkin Gelişimsel Perspektif

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ABSTRACT

Management of chronic health conditions in pediatric practice requires a holistic and systematic approach for optimal development. Although a substantial body of literature exists on chronic disease and health management across various chronic health conditions, there is a need for holistic approaches to achieving the optimal developmental potential of these vulnerable groups of children. This article reviews the developmental and behavioral effects, the hospitalization process, and the clinical management of chronic health conditions in children and provides specific recommendations. Chronic health conditions both affect and are affected by the development and behavior of children. Clinicians should be aware that chronic conditions affect all family members. To minimize the adverse effects of the disease, the unmet needs of children and their families should be identified, and supportive approaches should be implemented throughout illness and hospitalization. Specific pediatric roles, including coordination of care, identification of developmental-behavioral functioning, assessment of family strengths, education about the disease, and planning for schooling, should be integrated into standard pediatric care for effective management of chronic conditions.

Keywords: Chronic diseases, child development, pediatric practices, hospitalization, clinical management

ÖZ

Pediatri uygulamalarında kronik sağlık sorunlarının yönetimi, optimum gelişim için bütüncül ve sistematik bir yaklaşım gerektirir. Çeşitli kronik sağlık sorunlarına ilişkin kronik hastalık ve sağlık yönetimi üzerine önemli bir literatür bulunmasına rağmen, bu savunmasız çocuk gruplarının en iyi gelişim potansiyeline ulaşması için bütüncül yaklaşımı ihtiyaç vardır. Bu makale, çocuklarda kronik sağlık sorunlarının gelişimsel ve davranışsal etkilerini, hastaneye yatış sürecini ve klinik yönetimi incelemekte ve özgül öneriler sunmaktadır. Kronik sağlık sorunları, çocukların gelişimini ve davranışlarını hem etkiler hem de bunlardan etkilenen klinisyenler, kronik sorunların tüm aile üyelerini etkilediğinin bilincinde olmalıdır. Hastalığın olumsuz etkilerini en azı indirmek için, çocukların ve ailelerinin karşılanmamış ihtiyaçları belirlenmeli ve hastalık ve hastanede yatış süresince destekleyici iletişimler uygulanmalıdır. Bakım koordinasyonu, gelişimsel-davranışsal işlevselliliğin belirlenmesi, ailenin güçlü yönlerinin değerlendirilmesi, hastalık hakkında eğitim ve okul planlaması gibi belirli pediatrik roller, kronik sorunların etkili yönetimi için standart pediatrik bakıma entegre edilmelidir.

Anahtar Sözcükler: Kronik hastalıklar, çocuk gelişimi, pediatri uygulamaları, hastaneye yatış, klinik yönetim

Cite this article as: Çelen Yoldaş T, Developmental perspective on management of childhood chronic diseases in pediatric practices. Gazi Med J. 2026;37(1):126-134

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Received/Geliş Tarihi: 07.12.2024

Accepted/Kabul Tarihi: 12.04.2025

Epub: 24.11.2025

Publication Date/Yayınlanma Tarihi: 19.01.2026



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INTRODUCTION

The prevalence of chronic diseases in children has increased over recent decades owing to advances in treatments and care for life-threatening pediatric conditions and increased survival among children with serious congenital or acquired diseases (1). Chronic diseases comprise a wide variety of conditions in childhood and are typically defined by two main criteria. The first is the duration of the disease, which is usually 3-12 months or permanent. The second is severity, indicated by limitations in age-appropriate activities, prolonged or recurrent hospitalizations, or the need for special care (2). The term "chronic health condition" refers to both diseases and disabilities within the context of children's developmental and behavioral functions (DBF), as affected by multiple factors, including age, duration, limitations in age-appropriate activities, visibility, progression, and physiological, psychological, and social characteristics. The World Health Organization has also introduced the International Classification of Functioning, Disability, and Health to identify chronic health conditions at the levels of body structures and functions, activities and limitations, and participation and restrictions, considering a variety of facilitating or limiting environmental factors (2,3).

Chronic conditions themselves have a significant impact on children and their families due to pain, caregiving responsibilities, and financial burdens. Concurrent effects of DBF pose additional challenges for affected children and their families. Children with chronic health conditions must cope with the disease itself and its impact on emotional, behavioral, and developmental functioning. Distress experienced by family members disturbs family functioning and influences an affected child's emotional state (4).

Chronic health conditions commonly originate from multiple integrated constitutional and psychosocial factors. Although most diseases have biological etiologies, such as metabolic or genetic abnormalities, some conditions reflect primarily environmental and social factors, such as lead poisoning or preventable home accidents. Psychosocial factors also affect the course and severity of chronic disease. Children living in poverty have difficulty accessing coordinated health care (1,2). Previous research has shown that children with special health care needs in low-income families have substantially higher unmet health needs than those in high-income families (5).

Community factors, as facilitators and barriers, also influence families' ability to normalize life while caring for a child with a chronic disease or disability and working toward independent living (6). Chronic stressors experienced by the affected child and family members may lead to conflicts; therefore, they develop many individual coping strategies to regulate their emotions and solve problems (7). Clinicians should consider the preferred coping strategy rather than ignore it. If coping repertoires are restricted or their adaptive mechanisms are poor, clinicians should know how to support them in coping with the disease (6-8).

Management of chronic health conditions in pediatric practice requires a holistic and systematic approach to achieve optimal developmental and health outcomes (4). Although there is a large body of literature on chronic diseases and the management of many chronic conditions, there is a need for more research on the holistic clinical management of these vulnerable groups to achieve

optimal developmental potential (1,2,4). This paper aims to review developmental and behavioral effects, the hospitalization process, and the clinical management of chronic health conditions in children and provide specific recommendations.

Developmental and Behavioral Effects

The effect of chronic disease on the child's DBF depends on multiple, interrelated variables, including disease characteristics, such as whether it is congenital, as well as child, family, and social factors (2,4). For optimal health outcomes, clinicians should thoroughly understand the integrated factors that influence the DBF of children with chronic health conditions (Figure 1). The appropriate attitudes of parents and clinicians are of great importance to the development of positive outcomes in children during adaptation to the disease and treatment (9). Chronic health conditions are associated with a wide range of DBF problems (4,10). A national survey in the United States (US) conducted by the Centers for Disease Control and Prevention reported that parents of children with chronic health conditions were 2-30 times more likely to report attention-deficit/hyperactivity disorder, learning problems, and emotional and behavioral problems, with the highest rates among conditions involving the nervous or sensory systems (10).

Developmental Effects of Chronic Condition

Although development is a continuous, dynamic process, there are characteristic, age-specific developmental tasks, and chronic conditions may interfere with these tasks (2). The age at disease onset and the child's developmental stage particularly affect coping and adjustment (11). The more pervasive a chronic health condition, the more functioning is affected and the greater the challenge for the child and family. Progressive conditions pose significant challenges for family adaptation and expectations. Conditions with unpredictable courses are sources of chronic stress and maladjustment in the child and the caregivers. Conditions requiring frequent or prolonged hospitalization or isolation lead to parent-child attachment problems, unschooling, and difficulties with socialization and community participation. Children with a stable congenital condition, such as limb deficiency or hearing or vision deficits, commonly experience their condition as a difference rather than as a disease (2).

The factors that determine a child's reaction to a disease may be specific to the condition, treatment, family, and the child himself/herself; they interact with each other in a complex way (12). Developmental periods should be considered in order to understand the child's reactions to and understanding of the disease (9):

Infancy: The disease may adversely affect growth and pose caregiving challenges. The accompanying physical discomfort and changes in daily routines jeopardize the consistency and reliability of the baby's environment and undermine the development of basic trust (2,9).

Toddlerhood: They are prone to be more independent and curious, exploring their environment. Chronic diseases may delay the acquisition of developmental skills. The disease can create significant problems with parental competence and confidence, which may cause parents to exhibit overprotective or unfair attitudes that conflict with the toddler's or older child's increasing need for

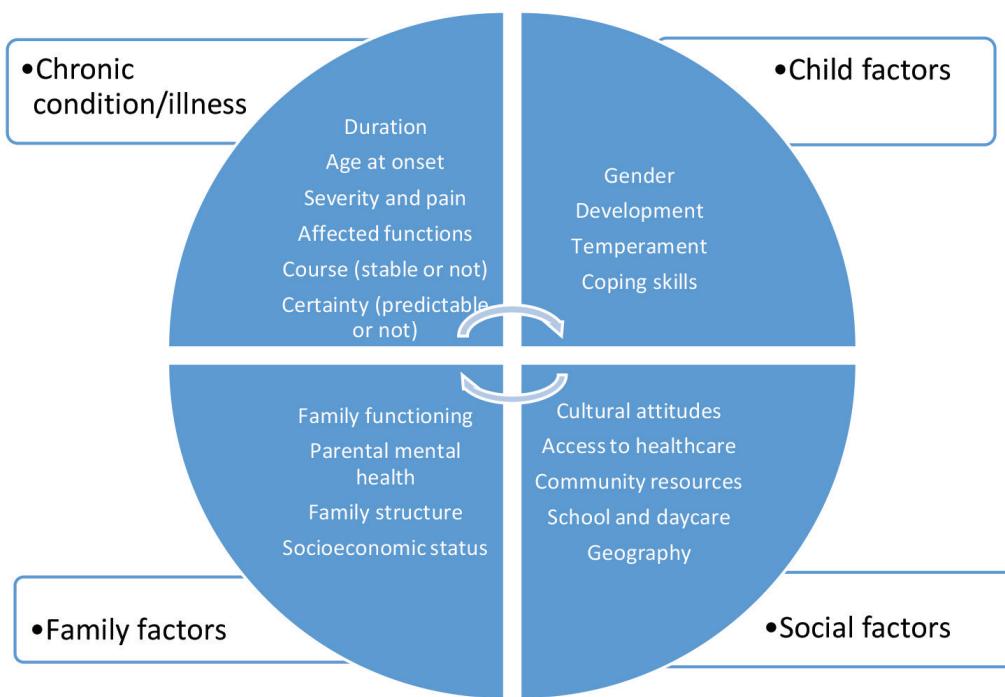


Figure 1. Integrated factors affecting the development and behavior of children with chronic health conditions.

independence, and these can undermine children's sense of self-control and autonomy (2,9).

Preschool period: Anxiety about separation from their parents and about physical harm is common. Egocentrism predominates, and they may perceive the disease as a consequence of bad behavior. Therefore, concerns about whether they will lose their parents' love or be separated from them take precedence over concerns about the name and nature of the disease. Distress may cause developmental regression in the child. The restrictions that parents impose on their children may make them fearful, passive, and dependent. Young children can reveal their feelings through behavior, play, or drawings (2,9).

School-aged children: Frequent absences due to the disease interfere with opportunities for learning and socialization. Children with physical differences must navigate peer acceptance while accepting their self-image. Restrictions due to disease or medical treatments cause fear of loss of control during this period. They can accept necessary procedures due to their increased comprehension and can describe specific complaints of their diseases. They may need to inquire about or discuss the condition. Therefore, brief and accurate information should be provided in an age-appropriate manner (2,9).

Adolescents: They must work to develop their identities and to maintain their educational and vocational goals while continuously managing their chronic condition. The limitations imposed by the chronic condition conflict with the increasing need for independence, which can negatively impact peer relationships and the development of secure sexual and physical identities. Gradual attainment of adult levels of disease understanding occurs during this period. Since many chronic diseases require dependence on caregivers, such

diseases are perceived as a loss of independence and a disruption of future plans. In addition, physical changes and disruption of school life constitute sources of psychological problems during this period. Informing adolescents about the disease and treatment, as well as sharing their feelings and thoughts, will help them adapt more readily (2,9).

Difficulties experienced by children with chronic diseases across different developmental periods are presented in Figure 2.

Importantly, chronic diseases may prevent the development of an appropriate individual identity in any child or adolescent. The presence of a disease may be more apparent than the presence of other individual characteristics. Adolescents themselves or clinicians often label those individuals as "diabetic" or "leukemic". Clinicians should use "people-first" language rather than "disease-first" language to encourage all involved (2).

Behavioral Effects of Chronic Condition

Community-based studies and meta-analyses commonly indicate an increased risk of behavioral and emotional problems in children with chronic conditions compared with healthy children, with an approximately twofold increase in risk (4,10). Overall adjustment problems, with increased rates of internalizing (anxiety, depression, withdrawal), externalizing (attention, hyperactivity, oppositional defiant disorder, conduct disorder), and low self-esteem, have been reported, regardless of the specific diagnosis (2). Parental adjustment is a determinant of the effect of chronic stress on the child. Many studies have shown a strong correlation between maternal mental health, particularly maternal depression and anxiety, and a child's emotional status (12-14). In a recent national study conducted among preschool children with chronic rheumatological diseases,

Infancy/toddler	Preschool	School ages	Adolescents
<ul style="list-style-type: none"> Sense of trust Chronic disease/pain Hospitalization and painful procedures Changes in eating habits Decreased growth Restrictions in movement Parent's sadness 	<ul style="list-style-type: none"> Autonomy Need for adult supervision and control Repeated separations Restrictions on movement and diet Decreased parental limit settings Restrictions on social settings with peers 	<ul style="list-style-type: none"> Sense of competence Need for adult supervision Limited independence Dependence on medical care Medical and dietary needs Activity restriction School absence Differences from peers 	<ul style="list-style-type: none"> Identity development Need for medical supervision Permanent dependency on parents Changes in body appearance Need for ongoing treatment or diet Occupational limitations Problems in sexuality

Figure 2. Difficulties of children with chronic diseases in different developmental periods.

maternal anxiety scores were positively associated with children's behavioral problems among those with familial mediterranean fever, a disease characterized by an unpredictable course. Internalizing problem scores were higher in children with chronic rheumatic diseases than in healthy children, suggesting the need for early childhood screening for developmental and behavioral problems to manage any chronic conditions (14).

The factors that positively affect the child's behavioral and emotional response to chronic disease are the following (12):

- 1) Dependence on family age-appropriately
- 2) Minimum need for secondary gains from the disease
- 3) Ability to withstand restrictions and responsibilities
- 4) Ability to develop satisfactory relaxing resources

Family Effects of Chronic Condition

The perception of the child as vulnerable is common among families who care for a child with a chronic health condition, and they usually act with varying degrees of protection, sometimes restricting the child's individual development (2). Each family develops their own coping strategies to adapt to the disease. Social and cultural factors influence their adaptation and are shaped by the context of family beliefs, myths, expectations, and roles (2,8,11).

Families whose child diagnosed with a chronic disease pass through a commonly predictable sequence of emotional reactions such as shock, denial, anger, stabilizing, and acceptance. However, these stages are not exclusive, crises may cause setbacks, and family members may go through different phases (12). Substantial hours of nursing care at home may affect family functioning, parenting attitudes, and individual independence. Although parents are generally willing to monitor their children's health, administer

medications, provide physical therapy, etc., they often report stress, fatigue, depression, and social isolation (7). Community-based studies have shown increased rates of mental health problems among parents, particularly high rates of depression or anxiety in mothers of children with chronic health conditions (13,15). Because caregiving tasks are usually attributed to mothers in families caring for a child with a chronic disease, mothers are less likely to work outside the home (12).

Parents also face economic burdens such as additional medical care costs, home environment requirements, transportation costs, and additional childcare needs. Lost income due to a parent's absence from work or missed career opportunities increase financial burden (16). Parents' economic problems may lead to marital tension. However, despite the stressful situations experienced by families caring for a child with a chronic disease, the frequency of divorce is no higher than that in the general population (17).

The parents' multiple tasks often limit the time available to siblings in families. Previous literature has yielded controversial results regarding sibling adjustment. Some have reported that living with a sibling who has chronic health conditions enhances maturity and skills and improves their resilience (18,19). Others have noted that siblings experience parental neglect, depressive symptoms, aggressive behavior, and academic failure (2,9,20). A recent meta-analysis has reported that siblings of children with chronic conditions have higher scores on depression rating scales compared with siblings of healthy children (20). Parental mental health and the family environment are the particular determinants of sibling adjustment. Clinical guidance emphasizes the importance of considering siblings and of encouraging a supportive family environment when caring for children with chronic diseases (18).

Families need multidimensional social support to cope better with their chronic conditions. Effective community resources, such as advocacy groups and condition-specific societies, may help parents obtain information and tangible support, as well as foster a sense of worth. Clinicians should shift their focus from providing solely targeted treatment to fostering family partnership, given this population's complex needs within the individual's social context (2).

Recommendations for Management

Difficulties in DBF differ by the developmental age periods which should be considered to understand the reactions and comprehension of the disease of the child. Clinicians should know that all family members are affected by chronic conditions. Frequently encountered problems such as overprotective parental attitudes and non-compliance with the treatment process can be prevented by health personnel approaching the family and the child with open communication and understanding their needs, informing them about the disease or treatment, and also maintaining effective communication within the family. To minimize the adverse effects of the disease, the unmet needs of children and their families should be identified, supportive programs should be developed, and the quality and quantity of services provided to children and families, as well as research on these issues, should be increased.

Hospitalization Process

Hospitalization is a universally significant source of stress due to separation anxiety, disruption of daily routines, unfamiliarity with the environment and people, and pain and fear associated with the disease and its treatment (21,22).

Both the child and the family require planning for hospitalization to enhance their ability to adapt by reducing their anxiety during hospitalization (22). Some innovative programs, techniques, and approaches have been developed to help children and families cope more effectively with the stress associated with hospitalization (23). Educational interventions for siblings of hospitalized children are also beneficial (24).

Children's Reactions to Hospitalization

Emotional difficulties are greatest among children aged 6 months to 6 years and increase particularly if hospitalization is long or recurs frequently. Separation from parents and other important family members is difficult for children because of their physical, social, and cognitive immaturity and their close, dependent relationships with their parents. In older children, it is perceived as a loss of independence; in adolescents, as a disruption of plans for the future. Some react verbally, whereas others react behaviorally (22).

The suggestions for all age groups include performing treatments at home whenever possible, using day-care units, limiting invasive, painful procedures, providing information according to the child's developmental level before procedures, and minimizing hospitalizations. Parents may also experience anxiety and a loss of control when their children are hospitalized, potentially affecting their children's responses (9). The following techniques can be used to reduce the stress of both the child and the parents (9,22):

The Techniques to Minimize the Stress Associated with the Hospitalization

Before hospitalization:

- Provide general education about child health and diseases through media and schools.
- Provide pre-hospitalization tours, videos, and educational materials (e.g., brochures and coloring books).
- Include the child and parents in decisions and discussions about procedures and hospitalization.

During the hospitalization:

- Minimize the length and number of hospital stays.
- Encourage and facilitate the visits by family members and friends.
- Provide child-life programs (fun and therapeutic play) and hospital school programs.
- Ensure continuity of care and minimize changes in doctors, nurses, and other healthcare staff.
- Provide family-centered care, parents accompany and support the child.
- Provide pain control, a limited number of procedures, and maximal mobility.
- Support personal care and the child's sense of self-control.
- Encourage ongoing interest from the peer group.

Hospital structure:

- Cheerful and child-oriented decor
- Developmentally appropriate toys and objects, play spaces to support cognitive and emotional well-being
- Comfortable accommodation for parents to facilitate family-centered care
- Waiting areas for parents near the operating or recovery rooms to reduce anxiety

Developmental Supportive Approaches for Pediatric Patients During Hospitalization

In addition to the psychological stress caused by hospitalization, biological stress resulting from the effects of disease and treatment on the central nervous system may lead to negative developmental trajectories in hospitalized children (25). Both biological and psychological risk factors increase cortisol secretion. Long-term high cortisol levels affect the function of the nervous system and cause structural changes in brain regions related to learning and memory, thus negatively affecting development (26).

The patient- and family-centered care approach, therapeutic play, child life services, hospital schools and educational activities, and pain control are recommended to prevent or reduce the negative effects of hospitalization on child development (23).

Patient and Family Centered Care Approach: Within this approach, healthcare professionals collaborate with the family to make joint decisions regarding disease treatment and related health processes. Involving families in their children's medical interventions or postoperative care reduces anxiety among children and families, reduces the need for analgesics, and accelerates postoperative recovery (27). Although the family-centered approach is well known,

its implementation is limited even in developed countries. In five years of national survey data from the US comprising responses from 36,675 parents of children with developmental or chronic health conditions, these parents were less likely to report that their healthcare provider always demonstrated the family-centered approach than parents whose children did not have any health conditions (28).

Therapeutic play: Play is vital for all children to cope more effectively with chronic stressful conditions. Through play, children re-enact daily life experiences and have the opportunity to participate in these experiences; thus, they reduce stress by developing a sense of internal control. Therapeutic play methods can transform the child's helpless and passive feelings into active feelings of control by creating scenarios in which anticipated sources of stress are managed (for example, by allowing the child to administer an injection to a doll). In these plays, the expression of feelings is encouraged, education about the hospital experience is provided, and physiological benefits are conferred (such as through the blow-out game to improve lung function) (29).

Child life services: Specially trained child life specialists provide an organized service known as "child life" in health centers in developed countries. These services aim to support child development through therapeutic play, educational activities, and other supportive activities during hospitalization (30).

Educational activities - Hospital schools: It is difficult for children with chronic diseases to attend school regularly due to long treatment periods and frequent hospitalizations. This restricts their opportunities for social development, disrupts school adaptation and success, and thus adversely affects children's developmental outcomes. Educational programs, called "hospital school programs", that follow the curriculum with professional teachers in hospitals have been initiated to support children's development during hospitalization in many countries (31).

Pain control: Management and treatment of pain should be the primary goal of pediatric care. Pain is a biological and psychosocial stressor that affects the development of hospitalized children. The perception of pain and its stress increase over time if adequate pain control is not provided. Children with chronic pain report higher levels of physical disability, anxiety, depression, and sleep problems as well as poorer academic performance and lower quality of life, compared with their peers (32).

Recommendations for Hospitalization

Clinicians should aim to promote optimal functioning in everyone involved in the process and to restore the family to normalcy as much as possible. Preparation for hospitalization is important for managing the condition. It is recommended that all family members involved in the process be informed about the disease, the evaluation, and the treatment. Information should be tailored to the developmental level of the child. Defenses such as denial and reflection should be expected. Open and sufficient communication establishes a sense of trust and competence in the child and the family, thereby increasing self-esteem, coping skills, and treatment adherence during hospitalization. The child should be allowed to express his/her feelings about the disease. What will be done should be explained before the procedures; however, it is necessary

to avoid unnecessary medical details and to be aware that anxiety and stress can impair the ability to understand what is heard. Many healthcare professionals underestimate young children's capabilities and do not attempt to communicate with them. It is also necessary to be available to listen to the child and family. Children whose parents have depression or anxiety and who receive less family support are considered at risk and should be referred to mental health services. The development of hospitalized children can be supported by reducing both biological and psychosocial stressors. The clinician's role during hospitalization is to minimize the distress and trauma while maximizing the benefits of care coordination (21).

Clinical Management of Chronic Health Conditions

The effective management of chronic conditions in children requires specific pediatric roles, including coordination of care, identification of DBF, assessment of family strengths, education about the disease, and school planning (2). Figure 3 presents the recommended pediatric management for children with chronic health conditions in clinical practice.

Coordination of Care

The medical home concept has been widely embraced as a primary care model for all children, initially to ensure coordinated care for those with chronic conditions. This model transforms the healthcare delivery system by avoiding fragmented care, overuse, or underuse; promoting interagency cooperation; alleviating stress for families;

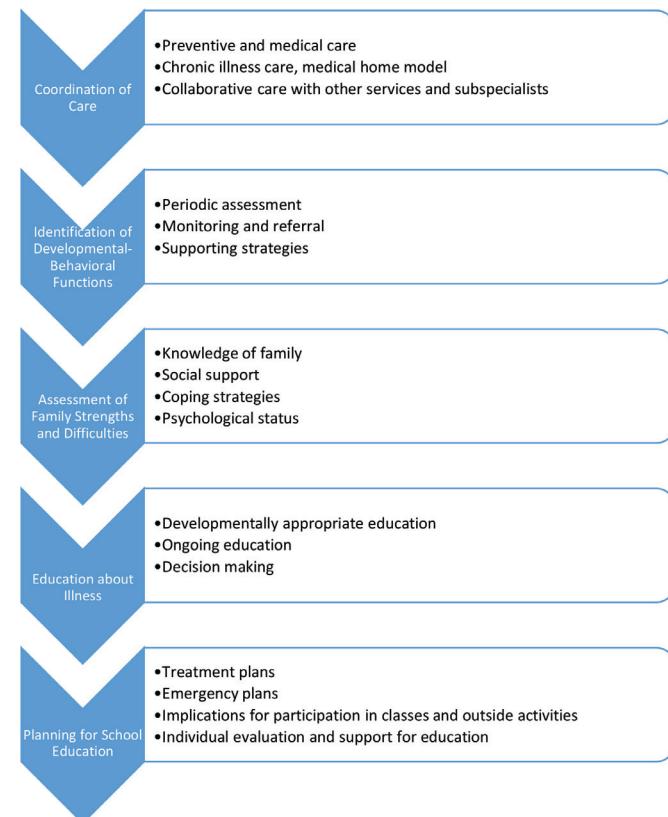


Figure 3. Recommended clinical pediatric management of children with chronic health conditions.

and ultimately improving outcomes such as health status, quality of life, and participation in school and the community. Following the registration of children with chronic health conditions, medical home providers, in addition to implementing standard medical care, provide children and families with access to educational materials and partner with families in decision-making, often in collaboration with other services and subspecialists (33).

Coordination of care entails developing an up-to-date family-centered care plan; helping the family learn about their child's care; facilitating access to needed services; establishing a network that connects all care providers, including social and educational services; and helping resolve conflicts among all parties. Social and emotional support for the family is also an integral part of care (34). Families usually need care coordination during the first year after diagnosis, during the adaptation process at discharge, and during particular transitional periods, such as schooling or transition to adulthood. They usually feel more competent in managing their child's needs and services as they acquire experience over time (11).

Identification of Developmental and Behavioral Functions

Children with chronic health conditions and their families require a wide range of services to meet their special needs. Through periodic assessments, clinicians can inform families about or help families access preventive mental health care, appropriate home nursing, educational and social services, and other specialized therapies (34). Healthy siblings of children with chronic health conditions are also at risk; therefore, the needs of other family members should be considered. Clinicians should ensure that all family members receive developmental monitoring and health supervision to prevent, identify, and manage the risks (27). Because of the high cost of health care for many chronic conditions, clinicians should also be familiar with both private and public referral sources in their region (33,34).

The clinician should be aware of the problems associated with DBF in children with chronic conditions and assess functioning and the need for referral (4,10). Developmentally supportive strategies should be discussed with families at every opportunity (14). Although most clinicians are willing to identify DBF in their patients with chronic conditions, they face multiple barriers, including a lack of time, training, and resources for referral. Therefore, a high proportion of children and families have unidentified developmental, behavioral, and mental health needs (35).

Assessment of Family Strengths and Difficulties

Clinicians should identify families' knowledge, social support, and coping strategies; help them increase support, if necessary; recognize difficulties and unmet needs; and strengthen skills for coping with and nurturing their child. If coping strategies are inadequate, clinicians should direct them toward strategies such as empowerment, self-management skills, and task sharing to help them cope with their diseases. Additionally, clinicians should be sensitive to maternal depression and marital dysfunction and know how to identify these problems and provide referrals when necessary. Telehealth, respite care, socio-emotional support, insurance and employment benefits, and parenting support are promising approaches to reduce stress and improve parental health and well-being in the clinical management of chronic health conditions. Parents are likely to

benefit from interventions tailored to their needs at different time points along their child's chronic disease trajectory (36).

Education about disease

Patient education is a key component of patient engagement, supporting them in managing their lives with chronic conditions. Structured educational programs enhance knowledge, self-management skills, and autonomy. In a scoping review on children, patient education was found to be beneficial in terms of decreased use of emergency care, hospitalizations, and visits to general practitioners, as well as fewer missed school days (37). Education about the disease and treatment should be given according to the developmental level of the child and the comprehension abilities of the parent. Education for the child is a continuing process as the child develops cognitively. On the other hand, families may receive much confusing information from different providers; clinicians can clarify knowledge for the families. Clinicians should communicate effectively with families and other providers and remain current on the related health condition (27).

Partnership in decision-making has expanded tremendously during the last decades. Parents accept more responsibilities in care now. Through the transition to adulthood, children take more responsibility to learn self-management of their chronic condition. When children and adolescents are actively involved in decision-making in their health care, they are usually better informed, thereby facilitating and benefiting the work of the health professionals (38).

Planning for School Education

Many children with chronic health conditions need satisfactory planning for school education. Due to school being the main workplace of children, clinicians should consider the school requirements. Some families need the support of their doctors to adjust school needs for their children. Some children need special education services because of the impact of their diseases on social and cognitive development. Some children with chronic health conditions cannot participate in standard education curriculums, requiring modifications of school days or class environment. Some require planning for medication or emergency care at school. School staff often need education about the disease and the necessity and results of schooling in the context of chronic conditions. Clinicians should work in collaboration with schools and families to ensure the best school placement (2).

CONCLUSION

Chronic health conditions both affect and are affected by DBF in children. Clinicians should know that all family members are affected by chronic conditions. Therefore, the unmet needs of children and their families should be determined, and supportive approaches should be implemented during illness and hospitalization. Specific pediatric roles, such as coordination of care, identification of DBF, assessment of family strengths, education about the disease, and school education planning, should be integrated into standard pediatric care for effective management of chronic conditions in children. Given the complexity of managing chronic health conditions for children and their families, holistic pediatric involvement with interdisciplinary collaboration and care coordination is necessary.

Footnotes

Conflict of Interest: No conflict of interest was declared by the author.

Financial Disclosure: The author declared that this study received no financial support.

REFERENCES

- van der Lee JH, Mokkink LB, Grootenhuis MA, Heymans HS, Offringa M. Definitions and measurement of chronic health conditions in childhood: a systematic review. *JAMA*. 2007; 297: 2741–51.
- Thyen U, Perrin JM. Chronic health conditions. In: Carey WB, Crocker AC, Elias ER, Feldman HM, Coleman WL, editors. *Developmental and Behavioral Pediatrics*. 4th ed. Philadelphia: Saunders Elsevier; 2009. Available from: <https://www.elsevier.com/books/developmental-and-behavioral-pediatrics/9781416033707>.
- World Health Organization. International classification of functioning, disability and health: ICF. Geneva: World Health Organization; 2001. Available from: <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>.
- Blackman JA, Gurka MJ, Gurka KK, Oliver MN. Emotional, developmental and behavioural co-morbidities of children with chronic health conditions. *J Paediatr Child Health*. 2011; 47: 742–7.
- van Dyck PC, Kogan MD, McPherson MG, Weissman GR, Newacheck PW. Prevalence and characteristics of children with special health care needs. *Arch Pediatr Adolesc Med*. 2004; 158: 884–90.
- Macdonald M, Lang A, Savage E, Chappe V, Murphy A, Gosse F, et al. Working to have a normal life with cystic fibrosis in an adherence-driven health care system. *Respir Care*. 2019; 64: 945–52.
- Smith S, Tallon M, Clark C, Jones L, Morelius E. "You never exhale fully because you're not sure what's next": parents' experiences of stress caring for children with chronic conditions. *Front Pediatr*. 2022; 10: 902655.
- Rinaldi Carpenter D, Narsavage GL. One breath at a time: living with cystic fibrosis. *J Pediatr Nurs*. 2004; 19: 25–32.
- Özmert EN. Gelişimsel pediatri. In: Yurdakök M, editor. *Yurdakök Pediatri*. Ankara: Güneş Tip Kitabevi; 2017. Available from: <https://www.guneskitabevi.com/yurdakok-pediatri>.
- Blackman JA, Conaway MR. Developmental, emotional and behavioral co-morbidities across the chronic health condition spectrum. *J Pediatr Rehabil Med*. 2013; 6: 63–71.
- Tluczek A, Grob R, Warne E, Van Gorp S, Greene L, Homa K. Parenting children with cystic fibrosis: developmental acquisition of expertise. *J Dev Behav Pediatr*. 2022; 43: 463–72.
- İnal N, Pekcanlar A. Chronic illness, hospitalization and child. *DEÜ Tip Fakültesi Dergisi*. 2008;22(2):99–105. Available from: <https://dergipark.org.tr/en/pub/deutipfak/issue/4683/64162>.
- Fraser LK, Murtagh FE, Aldridge J, Sheldon T, Gilbody S, Hewitt C. Health of mothers of children with a life-limiting condition: a comparative cohort study. *Arch Dis Child*. 2021; 106: 987–93.
- Çelen Yoldaş T, Özdel S, Karakaya J, Bülbül M. Developmental and behavioral problems of preschool-age children with chronic rheumatic diseases. *J Dev Behav Pediatr*. 2022; 43: e162–9.
- Barker MM, Beresford B, Fraser LK. Incidence of anxiety and depression in children and young people with life-limiting conditions. *Pediatr Res*. 2023; 93: 2081–90.
- Fitzgerald C, George S, Somerville R, Linnane B, Fitzpatrick P. Caregiver burden of parents of young children with cystic fibrosis. *J Cyst Fibros*. 2018; 17: 125–31.
- Sabbeth BF, Leventhal JM. Marital adjustment to chronic childhood illness: a critique of the literature. *Pediatrics*. 1984; 73: 762–8.
- Deavin A, Greasley P, Dixon C. Children's perspectives on living with a sibling with a chronic illness. *Pediatrics*. 2018; 142: e20174151.
- Woodgate RL, Edwards M, Ripat JD, Rempel G, Johnson SF. Siblings of children with complex care needs: their perspectives and experiences of participating in everyday life. *Child Care Health Dev*. 2016; 42: 504–12.
- Martinez B, Pechlivanoglou P, Meng D, Traubici B, Mahood Q, Korczak D, et al. Clinical health outcomes of siblings of children with chronic conditions: a systematic review and meta-analysis. *J Pediatr*. 2022; 250: 83–92.
- Rauch DA; Committee on Hospital Care; Section on Hospital Medicine. Physician's role in coordinating care of hospitalized children. *Pediatrics*. 2018; 142: e20181503.
- Perrin EC, Shipman D. Hospitalization, surgery, and medical and dental procedures. In: Carey WB, Crocker AC, Elias ER, Feldman HM, Coleman WL, editors. *Developmental and Behavioral Pediatrics*. 4th ed. Philadelphia: Saunders Elsevier; 2009. Available from: <https://www.elsevier.com/books/developmental-and-behavioral-pediatrics/9781416033707>.
- Atay G, Eras Z, Ertem İ. Developmental support of children during their hospitalizations. *J Child*. 2011; 11: 1–4.
- Gursky B. The effect of educational interventions with siblings of hospitalized children. *J Dev Behav Pediatr*. 2007; 28: 392–8.
- Armstrong FD. Neurodevelopment and chronic illness: mechanisms of disease and treatment. *Ment Retard Dev Disabil Res Rev*. 2006; 12: 168–73.
- Mueller SC, Maheu FS, Dozier M, Peloso E, Mandell D, Leibenluft E, et al. Early-life stress is associated with impairment in cognitive control in adolescence: an fMRI study. *Neuropsychologia*. 2010; 48: 3037–44.
- Committee on Hospital Care; Institute for Patient- and Family-Centered Care. Patient- and family-centered care and the pediatrician's role. *Pediatrics*. 2012; 129: 394–404.
- Brannon GE, Ray MR, Lark P, Kindratt TB. Influence of pediatric patients' developmental or chronic health condition status as a predictor of parents' perceptions of patient- and family-centered care. *Health Commun*. 2022; 37: 880–8.
- Nijhof SL, Vinkers CH, van Geelen SM, Duijff SN, Achterberg EJM, van der Net J, et al. Healthy play, better coping: the importance of play for the development of children in health and disease. *Neurosci Biobehav Rev*. 2018; 95: 421–9.
- Romito B, Jewell J, Jackson M; AAP Committee on hospital care; association of child life professionals. Child life services. *Pediatrics*. 2021; 147: e2020040261.
- Caggiano G, Brunetti LIG, Ho K, Piovani A, Quaranta A. Hospital school program: the right to education for long-term care children. *Int J Environ Res Public Health*. 2021; 18: 11435.
- World Health Organization. WHO issues new guidelines on the management of chronic pain in children. Geneva: World Health Organization; 2021. Available from: <https://www.who.int/news-room/01-02-2021-who-issues-new-guidelines-on-the-management-of-chronic-pain-in-children>
- Lerner CF, Klitzner TS. The medical home at 50: are children with medical complexity the key to proving its value? *Acad Pediatr*. 2017; 17: 581–8.
- Council on Children with Disabilities; Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics*. 2014; 133: e1451–60.
- Rhodes A, Sciberras E, Oberklaid F, South M, Davies S, Efron D. Unmet developmental, behavioral, and psychosocial needs in

children attending pediatric outpatient clinics. *J Dev Behav Pediatr.* 2012; 33: 469–78.

36. Bradshaw S, Bem D, Shaw K, Taylor B, Chiswell C, Salama M, et al. Improving health, wellbeing and parenting skills in parents of children with special health care needs and medical complexity - a scoping review. *BMC Pediatr.* 2019; 19: 301.

37. Stenberg U, Haaland-Øverby M, Koricho AT, Trollvik A, Kristoffersen LR, Dybvig S, et al. How can we support children, adolescents and young adults in managing chronic health challenges? A scoping review on the effects of patient education interventions. *Health Expect.* 2019; 22: 849–62.

38. Quaye AA, Coyne I, Söderbäck M, Hallström IK. Children's active participation in decision-making processes during hospitalisation: an observational study. *J Clin Nurs.* 2019; 28: 4525–37.